

# Should Patients Pay to Play?

By Ezekiel J. Emanuel  
and Steven Joffe

**A** FEW months ago, we got a call from a former oncology professor of ours. He had developed an experimental precision diagnostic test that he thought would be able to determine which chemotherapies would be most effective against a patient's cancer. He wanted to conduct a research trial to evaluate the effectiveness of the new test. But there was one big problem: The research had no funding.

He wanted our view on whether it would be legal and ethical if he charged the patients about \$30,000 each to pay for the research.

This idea is not as outlandish as it sounds. In the 1980s some for-profit companies and institutes charged patients for participating in research. Mostly they went bust. Recently, others have proposed that the rich buy places in clinical trials. And now scientists have begun thinking this may be a way to fund promising research ideas.

The rationale behind the request was understandable. The researchers were frustrated. Ideas about potential tests and treatments for diseases like cancer, multiple sclerosis and Alzheimer's disease are not being tried out because of a lack of research funds. If a research study otherwise fulfilled all the requirements for a good scientific and ethical study — it has a clear and compelling hypothesis, a detailed protocol, would be reviewed by the cancer center's research ethics committee, all participants would sign informed consent documents and the results, positive or negative, would be disseminated in the scientific literature — why shouldn't patients be

*Ezekiel J. Emanuel and Steven Joffe are professors in the Department of Medical Ethics and Health Policy at the University of Pennsylvania.*

charged?

Supporters have what appears to be a good case. Charging would result in more research, and the more research that is done, the more society learns about which drugs, devices and diagnostic tests work and which don't. By charging, otherwise fallow ideas could be tried. And even if the results are negative, society learns what leads not to pursue. This kind of "pay-to-play" research would be a form of crowdfunding, a kind of Kickstarter for clinical research.

Few people would sign over \$30,000 without carefully scrutinizing the proposal.

Finally, there is the matter of individual liberty. Traditionally we believe that people should be able to do whatever

---

**It could subsidize  
promising experiments.  
But is it ethical?**

---

they want as long as they do not harm others or infringe others' rights, liberties and opportunities. Buying a place in a research study that would otherwise not be conducted does not hurt anyone else. Preventing people from spending their own money to participate in research infringes on their liberty. Spending one's money to be in research certainly is more valuable than spending it on fancy dinners, a watch or season sports tickets.

Despite some apparently good arguments, we disagree with this approach. While there is no law or rule that would prohibit pay-to-play research, and some research may be funded this way, as we wrote in the current issue of *Science Translational Medicine*, we think charging would be a mistake.

Many people are willing to try almost anything for themselves or a loved one,

especially a young child with a terminal illness. In many cases it will be impossible to know the chances of success. Yet desperate, hopeful people — as well as researchers — often significantly overestimate the odds that early-stage research, such as our professor's precision medicine test, is the least likely to benefit patients. Indeed, only about one in 10 drugs that enter early-stage testing is ultimately F.D.A.-approved. Lots of good research that is worth doing produces negative results. Nevertheless, the most promising leads are likely to secure funding for their research.

And just because a person could write a check to enroll in a research study does not mean he or she cannot be taken unfair advantage of. That is where government usually steps in to protect people.

Even more worrisome is how payments might undermine the research enterprise. Researchers might shift the direction of their work to cater to the well off who can pay to be in their studies. They might work on diseases of the rich rather than public health measures focusing on the poor.

Then there is the problem of compromising the conduct of a research trial. It is not hard to imagine researchers bending the inclusion criteria to include a paying patron and then not removing that person from a study, or deciding to continue a study, because the investing participants want it to continue. Indeed we have witnessed many people wanting to take a drug proved ineffective, such as Avastin for metastatic breast cancer, because they believe — despite the data — that it works for them.

By charging participants, maybe a few experimental tests and treatments that would not be pursued under today's tight research budgets would be funded, and maybe one or two would succeed. But the risks are not worth taking. We must avoid compromising the integrity of the entire research enterprise and the likelihood of exploitation that will inevitably accompany pay-to-play trials. □